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ABSTRACT

This report of a conference session dealing with recreation and leisure activities for people with deaf-blindness and other profound multiple disabilities contains three papers and a working group report. The title paper by Lori Goetz reviews "model indicators" for recreation and leisure educational programming with individuals who have severe and profound disabilities, reviews services currently available, and makes recommendations for future programming. In their response, titled "Importance of Communication Skills and Their Etiology in Planning of Recreation and Leisure Programs for Persons with Multiple/Profound Handicaps of Deafness and Blindness," Pamela Mathy-Laikko and Terrence Dolan comment on individual differences, integration of deaf-blind and noncompromised children and adults, the issue of choice-making, and the need for training and advocacy to improve recreation/leisure opportunities for handicapped individuals. Another response, by Barbara Ryan, provides a parent's viewpoint of the challenge of providing age-appropriate recreational activities for her handicapped daughter and the use of a hired companion to assist in meeting the challenge. Finally, the Working Group on Recreation and Leisure presents a report of its philosophy, program approach, program characteristics, issues, and recommendations. (JDD)

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SECTION IV: RECREATION AND LEISURE

Recreation and Leisure: Practices in Educational Programs Which Hold Promise for Adult Service Models

Lori Goetz

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Introduction

The current state of the art in recreation and leisure programs and services for persons with severe multiple disabilities has been comprehensively reviewed by several authors (Compton, Burrows, & Witt, 1979: Putnam, Werder, & Schleien, 1985; Voeltz, Wuerch & Wilcox, 1982; Wehman & Schleien, 1981). Based upon my own background, the focus of this paper will be upon what we know to be "model indicators" for recreation and leisure programming in educational contexts with school-aged individuals who have severe and profound disabilities including dual sensory impairments. With those indicators identified, I will review services currently available to young adults and their families in transition, and offer some initial suggestions on how we might integrate knowledge gained from school-based programs with current programs provided by community-based service agencies. It is hoped that these suggestions will serve as a starting point for our small group discussions.

Definitions: What Is Leisure? What Is Recreation?

The dictionary defines leisure as "freedom from time-consuming duties or activities," and recreation as "refreshment of the mind or body after labor through diverting activity." Neither definition provides much concrete information to agencies and/or individuals seeking to improve recreation and leisure services for a specific group of people. While a precise definition remains elusive, several components of recreation and leisure are important to note:

Discretionary time (Putnam et al., 1985; Voeltz et al., 1982). Leisure and recreation take place when an individual is not doing the other activities, duties, and responsibilities that are required of him (usually by someone else). For school-age students, leisure takes place before, after, or between required activities that occur at home, at school, or in the community. For transition-aged young adults, leisure and recreation take place before, after, or between required activities in the workplace, at home, and in the community. This variability in the times (and therefore also in the places) when leisure skills are needed and used means that an individual's leisure and recreational skill needs affect all other domains and environments in which she participates. (Recreation may take place during a break at work, after dinner at home, and in a community recreation center on the weekend.)

Variable location. As mentioned above, variable locations are another component of the recreation leisure domain. Persons recreate in all sorts of different places: there is nothing about leisure and recreation that restricts it to specified "leisure" environments. However, leisure-specific environments also exist, including park and recreation agencies (municipal recreation centers), community education agencies, and voluntary clubs (YMCA), with services available on both an episodic and sporadic basis. Thus, both when and where people recreate is based on highly individual factors.

I would like to thank both Dr. Terry Dolan and Barbara Ryan for their thoughtful commentaries and add that I very much agree with their remarks. Dr. Dolan's comment concerning the importance of communication skills for deaf-blind individuals is an excellent one. I think, in relation to making and expressing choices, we need especially to remember that persons with dual sensory impairments may express their preferences in ways which are nonconventional, idiosyncratic, and not reflective of standard language systems or communicative forms of behavior (see Donellan, Mirenda, Mesaras, Fassbender, 1984). Failure to use a conventional form to express choice should not result in denial (intentional or unintentional) of an expressed leisure preference; service providers must therefore possess skills that go beyond only recreation and leisure to understanding and utilizing the communication system that any person uses.

Personal choice (Bull, 1972; Murphy, 1981; Voeltz et al., 1982). Recreation and leisure activities provide ideal opportunities for people to exercise choice and personal preferences. A leisure activity is defined in part by the fact that it is something an individual chooses to do, versus something that an individual is required to do. Indeed, some investigators have suggested that the omission of choice in the participation process may prevent individuals from genuine leisure experiences (Datillo & Barnett, 1985). Certainly, if one indicator of quality of life is the number of choices available to an individual, then both the skills and the opportunities needed to exercise meaningful choices are essential components of recreation and leisure.

Variability in the time and place when recreation is experienced, combined with the role of personal preference and choice in leisure results in several unique implications for service delivery. The first has to do with the types of recreation and leisure skill needs that individual young adults in transition and their families might have. If an individual is to exercise choices and enjoy recreation and leisure across a range of times and places, he or she needs two different types of leisure behaviors.

1. Isolate (solitary)/individual skill activities that allow an individual to recreate in the absence of a formal time, place, or social context for recreation. For example, after completing participation in dinner clean-up activities in a group home, a person might still have two hours of discretionary leisure time until it is time to prepare for bed; or when arriving early for an appointment to have a haircut, an individual has ten minutes of discretionary time to use according to her personal preference. In traditional taxonomies, these activities are often categorized as hobbies, crafts, arts (Institute for Career and Leisure Development, 1978); object manipulation skills (Wehman, 1979); or sensory stimulation activities (Granger & Wehman, 1979). Regardless of how they are categorized, these activities are self-reinforcing: They are engaged in for the pleasure that is derived from the doing of them, and do not necessarily require a social context to be enjoyed.
2. Community (shared) participation activities is recreation which allows an individual to participate in a wide range of community-based recreation programs and events along with others. For example, an individual might wish to join a painting class, visit a museum, become a member of a ball club, or go on a camping trip. In traditional taxonomies, these activities might be called sports and physical development, play and games, outdoor activities, or entertainment and cultural events. Again, regardless of how these activities are formally clasified, they involve a social context, either through formal agencies outside the home, or through informal use of the social environments available at work, at home, or with community.

Youth who are deaf-blind and are in transition, then, have a need for at least two different types of leisure and recreation—isolate solitary leisure skills and community referenced recreation—and should have both types reflected in their daily lives.

Goals

The unique time, place, and personal choice characteristics of recreation/leisure also result in two different sets of goals for service providers. Programs that provide recreation/leisure services must aim to both increase specific skill levels of participants and increase the range of opportunities and access to participation available to participants.

1. Increasing range of skills. A growing literature is documenting the role of choice in influencing both competence and pleasure in an activity (Datillo & Rusch, 1985; Guess, Benson, & Siegel-Causey, 1985; Shevin & Klein, 1984). In order to make meaningful choices, an individual must have a range of behaviors to select among.

If an individual has a limited number of skills, and he often spends his free time in repetitive self-stimulating behavior, it is a disservice to say that this is a preferred activity that the individual has chosen, and therefore his leisure needs have been met. Choice requires alternatives; alternatives require skill acquisition and mastery before an individual can be honestly said to have exercised his personal preference among a range of alternatives. Service providers must therefore be prepared to teach new skills (be they solitary or group participation activities) so that a person will have genuine recreation and leisure options.

2. Increasing range of opportunity/access. In addition to possessing the skills required to engage in a recreation/leisure activity, a second essential element of choosing meaningful recreation is the availability of, or access to, the context in which the recreation and leisure can take place. Developing an individual's reading skills is pointless without access to books; learning ball handling skills is purposeless if the individual cannot use his local recreation center, school playground, or neighborhood gyms. Recreation service providers must therefore not only provide new skills to the individual transition-aged student with dual sensory impairments, but they must also broaden the leisure opportunities available to him.

The service needs of transition-aged youth with severe multiple handicaps and their families are thus at least fourfold: these persons must have leisure and recreation repertoires that include both individualized isolated leisure and social context recreation activities; furthermore, service providers must offer both increased skill acquisition or learning, and increased opportunities to utilize these skills in the appropriate contexts.

Model Indicators/Best Practices: What Are They?

Having outlined what I believe are some essential and unique components of recreation/leisure, and what at least four major consumer service needs are, I would now like to address what we do know as "best practice" or "state of the art" practices in meeting these needs in educational (public school) settings. A number of authors have documented different aspects of these model practices with transition-aged youth and adults with severe multiple handicaps, including Hamre-Nietupski and her colleagues in Iowa (Hamre-Nietupski, Nietupski, Sandvig, Sandvig, & Ayres, 1984; Nietupski, Hamre-Nietupski & Ayres, 1984; Nietupski & Svoboda, 1982); and Schleien and his colleagues in Minnesota (Schleien & Larson, in press; Schleien, Olson, Rogers, & McLafferty, 1985; Schleien, Rynders, Mustonen, Fox, A., & Kelterborn, B., 1986; Schleien, Wehman, & Kiernan, 1981). Some of these practices are drawn from public school programs in the San Francisco Bay Area and include at least one federally funded model demonstration project, which I direct, that works specifically with students who are deaf-blind (Project CIPSSI, Community Intensive Programming for Students with Sensory Impairments, USOE Grant #G008430094). CIPSSI's goal is to develop and evaluate a model for inclusion of students with multiple profound disabilities, including dual sensory impairment, in a community-intensive (community-based), functional life skills educational program.

Voeltz et al. (1982) identified three global areas of concern in developing recreation and leisure curricula for persons with severe disabilities: normalization, individualization, and logistical environmental factors. I would like to expand upon each of these in terms of specific model indicators or "best practices."

Normalization includes at least the following concerns:

Integration with nondisabled peers. The benefits of integrated school programs, for both severely disabled and nondisabled students, have by now been widely documented. These include attitude change, positive affect, and increased motivation (Hamilton & Anderson, 1983; Park & Goetz, 1985; Voeltz, 1982; see also Taylor, 1982 for general review). Examples of integrated recreation programming range from a deaf-blind

adolescent mainstreamed into a P.E. class to a five-year-old participating in a kindergarten art activity at his school.

The dimension of integration, of course, raises questions about the role of "special" recreation programs, such as Special Olympics. The advantages of Special Olympics (increasing public awareness, providing success experiences, etc.) have been reviewed (Putnam et al., 1985) and should not be ignored. However, Special Olympics participation clearly cannot function as a lifelong leisure program for participants, any more than the Olympics serve as a lifelong recreation event for nondisabled participants. Special Olympics, therefore, cannot be the whole of an individual's recreation experience. If the dimension of choice is to be genuinely present, "special" recreation and leisure programs must be only one alternative among many others that include participation with nondisabled peers in "generic" recreation/leisure environments.

Chronological age-appropriate activities. Is the activity provided being taught something a nonhandicapped person would enjoy doing in his free time? (Brown et al., 1979). Nondisabled teenagers go to aerobics classes; nondisabled preschoolers play "Gotcha" and "Chicken Out," so these are activities we use in our school programs. This indicator is in direct contrast to a philosophy that says leisure can be anything an individual chooses. It is my experience that individuals with sensory impairments and severe handicaps "choose" age-inappropriate activities (i.e., light-gazing or finger-flicking) in part when they lack the skills to entertain themselves in other ways. In deciding on activities and contexts to teach as alternatives, age-appropriateness is a major normalization factor.

Referenced to NH peers. Providing and/or teaching skills, games, and leisure activities that are attractive, as well as appropriate, to chronological age peers is a further factor that facilitates normalization (Gaylor-Ross, Haring, Breen, & Pitts-Conway, 1984). When we go into the kindergarten with "Roger the Robot" adapted to a special switch, our students are provided with an entry into ongoing play; when a student shows up during lunch hour at the high school wearing a walkman, he gains access to the social context much more readily.

Occurrence in natural environments (Brown, et al, 1979). How much fun can playing baseball be if you can only use a plastic bat, and only hit the ball so hard because you "need" to learn baseball in the structured and safe environment of the classroom before you are "ready" to play baseball in the park? Using and/or teaching a recreation/leisure skills where it is needed makes sense in terms of learning efficiency and generalization problems (Sailor & Guess, 1983), but also in terms of motivation and fun, which is after all what recreation is supposed to provide. Turning the pages of a talking book is a bigger turn-on in the library with other kids your own age than it is at a desk in the classroom with your teacher.

Increase community access/participation. Recreation and leisure programs and/or activities that are integrated, chronologically age-appropriate, attractive to nondisabled peers, and occur in natural environments and social contexts will probably accomplish this last normalization criterion without any additional planning. Using a vending machine during a break at work, joining a game of Duck-Duck-Goose with the third graders, hanging out after lunch at local high school, going for a workout at the local gym, using a switch to listen to a radio while traveling to the park, and having a burger at McDonald's with your friends are all forms of leisure and recreation that enhance quality of life through normalized activity options.

Individualization includes at least the following concerns:

Respecting/facilitating choice. The unique role of choice in recreation/leisure behaviors has already been pointed out. Persons with severe multiple handicaps currently have relatively few options for choice and self-determination; as the field is attempting

to expand the role of preference in educational programs, leisure is a prime starting point. Preliminary evidence suggests that severely handicapped persons may experience greater pleasure when they select (in contrast to being assigned) to engage in a leisure activitiy (Datillo & Rusch, 1985); simply assigning an activity to someone to "enjoy" based solely upon its sensory feedback characteristics or motoric response requirements disregards the role of personal preference that is a hallmark of recreation activities.

If an individual has a range of recreation options (i.e., a variety of activities in which she is competent, or thats she can engage in with support or assistance), and she, upon occasion, chooses to engage in an activity that is not highly normalized, the recreation/leisure domain allows us to respect that choice. Integration of a person with disabilities into natural recreation environments requires adaptations on both sides. Too often, however, "choice," "preference," and "pleasure" are offered as a rationale for failing to teach new skills, which, in turn, further restricts genuine leisure options.

Increasing competence/skill acquisition. The role of competence in determining pleasure from an activity has long been addressed in the child development and infant literature (Harter, 1978; Ramey & Watson, 1972), and has recently received increasing attention in educational practices with learners with severe handicaps (Goetz, Schuler, & Sailor, 1982). People enjoy doing the things they are good at, and therefore one focus of an individualized leisure or recreational program should be to teach new skills and improve competence, so that activities can actually be enjoyable leisure options. Individuals with significant sensory and other handicaps may need to learn to play through structured, systematic instruction before the skill or activity can become a genuine recreation/leisure choice. (While recreation and leisure activities can often provide an excellent context for learning other skills such as motor skills, this is an educational issue that is secondary to the need for recreation and leisure activities, the primary purpose of which is to provide recreation and leisure.)

Addressing both individual/isolate and group context leisure needs. Every individual is entitled to a variety of recreation and leisure skills, such as activating a toy, listening to a record, working leathercraft, roller skating around the street, collecting stamps, or just painting fingernails, and group context recreation such as joining a "wave the parachute" game during recess, taking a swim class at the local Y, playing cards with siblings, or participating in a pep rally at the local college campus. Varied options are in direct contrast to what might be termed the "single solution" approach to leisure, in which all participants must participate in the same predetermined activity regardless of skill levels or interest levels, or in which leisure means doing the same thing at the same time in the same place because it is "leisure" time or "break" time.

Based upon individual and family style. An individual whose family enjoys playing table games will have little opportunity for increased participation if he primarily learns calisthenics and weightlifting skills in his recreation program. Conversely, an individual whose family spends a great deal of time outdoors hiking and camping will be poorly served by a leisure program that focuses upon clay modeling. Family preference is a significant planning factor, as are individual preference and individual skill levels. Assessment practices that address these issues are beyond the scope of this paper, and the reader is referred to Certo, Schleien and Humber (1983), and Wuerch and Voeltz (1982) for further discussion.

Logistical environmental factors. This area of concern addresses the practical matters of availability, expense, and safety of any given program or activity. A leisure program that is inaccessible to an individual through readily available transporation may be a luxury, and not truly functional long-term recreation. Leisure activities that involve costly equipment and/or materials may greatly enhance an individual's quality of life (e. g., a lift harness to provide access to a therapeutic swimming pool) but the burden of these costs has to be shared and costly alternatives cannot be the sole alternatives

available. Safety factors must be weighed against the dignity of risk: going to the soda fountain to enjoy a coke poses risks to a young girl who has been described as "medically fragile," but these risks must be weighed against the pleasure and self-esteem of being "just another third grader."

These examples of model indicators do not just "happen." Successful recreation and leisure, in which experiences are individualized, contribute to skill acquisition, reflect community norms, and facilitate interaction and participation with nondisabled peers, require several key elements. For example, the environments in which these people are recreating have been prepared through conscious inservice/staff development/awareness activities, and the personnel working with these students have training in individualized assessment and data based instructional procedures. I will return to these points later in the paper.

Current Status of Adult Services

Data on the status of leisure and recreation activities and programs for adults with profound handicaps including dual sensory impairment is extremely limnited. Some investigations have looked at leisure participation of persons with moderate to severe handicaps subsequent to deinstitutionalization or after leaving high school (Birenbaum & Re, 1979; Chesseldine & Jeffree, 1981; Gollay, Freedman, Wyngaarden, & Kurtz, 1978; Hill & Bruininks, 1981; Intaglia, Willer & Wicks, 1981), but even this data base is not comprehensive.

The literature that is available concerning individuals with moderate to severe disabilities does suggest at least three major factors influencing recreation/leisure lifestyles for young adults:

1. Families often shoulder the major responsibility for providing recreation and leisure activities and opportunities since personal friendships decline after individuals leave their school programs (Chesseldine & Jeffree, 1981).
2. Neither a successful vocational placement nor a successful community residential placement in itself guarantees a normalized leisure lifestyle (Birenbaum & Re, 1979; Intaglia et al., 1981).
3. Lack of participation in leisure activities is often due to practical factors, such as not having adequate transporation or not having someone to accompany the individual if needed (Hill & Bruininks, 1981) but is also often due to lack of skills in utilizing available leisure opportunities (Birenbaum & Re, 1979; Hill & Bruininks, 1981).

Clearly these three factors suggest that planned, systematic service delivery is going to be needed in order to accomplish effective recreation and leisure for deaf-blind youth in transition. Because leisure may occur at varied times and places when the individual is at home or at work, and because leisure is a matter of pleasure and personal choice, it appears that other agencies responsible for residential and vocational placement do not regard leisure as their primary responsibility. As a result, the data suggest that an individual's recreation/leisure needs often go unmet or are met solely by the individual's family.

What about the perspective of service providers and agencies whose primary responsibility is recreation and leisure for all citizens, including those with disabilities? The need for a comprehensive community service delivery system of recreation and leisure programming for persons with disabilities has been expressed in the literature (McGregor, 1982). However, in many instances, generic service agencies such as park and recreation agencies appear to be unaware of their roles and responsibilities in providing services (Austin, Peterson, Peccarelli, Binkley, & Lacker, 1977; Edgington, Compton, Ritchie, & Vederman, 1975; Schleien, Porter, & Wehman, 1979). As an example, Schleien and Werder (1985) recently completed a comprehensive survey of service providers in Minnesota.

Schleien and Werder included 323 public schools, park and recreation agencies, and community education agencies (all tax supported) in their needs assessment survey. Among their major findings were the following:

1. Each agency type believed that another agency should have primary responsibility for meeting the needs of citizens with disabilities.
2. Services offered were limited in both quantity and quality: recreational activities available to citizens with disabilities were based on instructor preferences rather than client preferences, and were not referenced to individual needs or skill levels; services also tended to be restricted to activities that were stereotyped "handicapped" activities (field trips) versus more normalizing activities (camping or spectator sports); and services were generally not integrated with nondisabled participants.
3. Less than 10% of the agencies employed a full-time professional to develop and implement programs for individuals with special needs.

Based on these findings, Schleien and Werder made a number of recommendations, including either transagency models or designation of a lead agency, such as, parks and recreation programs. Schleien and Werder also recommended increased support for training personnel, and that offered recreation services be consistent with a number of "best practives" that are outlined earlier in this paper.

When I was asked to prepare this paper, I also completed a small local phone survey of my own. While generalizations are not appropriate, I was surprised to find many similar concerns to those expressed by Schleien's respondents. My sample included both park and recreation agencies (five recreation centers in San Francisco), the public library branch, and two private nonprofit agencies (YMCA and the Jewish Community Center). In every instance, when asked about including, enrolling, or serving an individual with extensive special needs within their regularly provided programs, the agency indicated no anticipated difficulties and did not refer me to a "handicapped only" program. In each instance, the agency requested that supervision be provided so that the participant could benefit from the activity being offered. Thus, a willingness to serve, but coupled with lack of information, leadership, or perceived responsibility for facilitating participation, concurs with some of Schleien's findings as well.

What's Next?

In summarizing the various findings from adult and generic service providers, while keeping in mind the "best practices" characteristics that should be present when providing services, I suggest that at least the following needs must be addressed if transition-aged youth with handicaps of deafness and blindness and their families are to enjoy a genuine leisure lifestyle:

1. Expand the role of recreation as a related service, and mandate inclusion of recreation and leisure program services in IEPs (Individual Educational Plan under PL 94-142) and ITPs (Individual Transition Plans) for transition-aged youth. The National Consortium in Physical Education and Recreation for the Handicapped (Ramey & Watson, 1985) has discussed many of these issues in a position paper prepared for the Office of Special Education Programs.
2. Designate a lead agency with primary responsibility for providing appropriate recreation/leisure activities, opportunities, and skill acquisition to persons with severe multiple handicaps. By designating a generic agency (i. e., one that serves all citizens) many of the model practices can be more easily accomplished than they could be by utilizing a "special" service agency. Schleien and Werder suggest that Parks and Recreation be the lead agency. I think this is one of many issues we can discuss at this conference.

3. Within the designate lead agency, explore and develop new professional roles that will enable the agency to successfully serve persons with profound disabilities. Some alternatives to consider might include the following:
   "Recreation coaches" based upon the model of job coaches (Wehman, Hill, Goodall, Cleveland, Brooke, & Pentecost, 1982), whose role is to identify and match client to job, provide initial intensive job training, and then be available for intermittent follow up in the workplace. Similarly, a recreation coach's role might be to match individualized participant needs with a set of existing programs, provide skill training as needed to the participant and to the service provider, and to provide follow up on an intermittent basis and continue to create new opportunities in accord with individual and family preference or needs.
   "Supported Recreation" based upon the model of supported work for those individuals with significant disabilities that preclude complete independence in the workplace (Brown et al., 1983). A supported recreation model is appropriate for those persons who require ongoing assistance to enjoy and benefit from structured recreation/leisure programs. As in the supported work model, a number of different persons might actually provide this support (a co-participant) with the professional providing initial intensive training. The notion of "companionships" (Salzberg & Langford, 1981) in which disabled and nondisabled persons are matched on the basis of shared leisure interests is another option which enables persons with significant disabilities to be full participants in recreation and leisure.
4. Prepare community agencies through inservice and awareness training prior to actually providing services. An extensive literature exists on how to integrate persons with handicaps into a "generic" agency such as a public school. Models for awareness training of co-participants, extensive media, and resource libraries are available and have been demonstrated to influence the success of an integration effort (Sailor, Anderson, & Halvorsen, 1985). Similar materials need to be developed that are appropriate to community service agencies and indeed some are already underway (Bullock, 1986; Schleien & Ray, 1986). Once developed, this process should occur on a systematic basis with all generic service providers.
5. Provide personnel training in the areas of therapeutic recreation, adaptive P. E., and special education to close the gaps between professional areas of expertise and to prepare persons for new professional roles (#2 above). Currently, therapeutic recreation professionals have strengths in the areas of adapting activities and utilizing community resources; however, they may be unfamiliar with both the new population they will be asked to serve and with the philosophy of model practices in services for these individuals. Conversely, special education personnel may have extensive knowledge of specialized needs and training procedures but are often unaware of the resource available in the "generic" community.

Given the size of the task, this is a fairly short list of recommendations. Major issues, including costs, responsibility for program monitoring, and family involvement with adult service agencies have not been addressed. Principles of partial participation and adaptation (Baumgart et al., 1982) and structured individualized instruction (Sailor & Guess, 1983), both of which are integral to effective services for persons with multiple profound disabilities, have barely been touched upon. However, I hope that I've made a convincing case that an individual's recreation and leisure needs are every bit as crucial and valid as his or her need to live in an appropriate and comfortable residential setting and to work at a job that provides social and economic compensation. The fact that leisure occurs in, around, and between all the other things that we do in no way decreases its importance in determining quality of life for everyone.

References

Austin, D., Peterson, J., Peccarelli, L., Binkley, A., & Lacker, M. (1977). Therapeutic recreation in Indiana: Health through recreation. Bloomington, Indiana University, Department of Recreation and Park Administration.

Baumgart, D., Brown, L., Pumpian, I., Nisbet, J., Ford, A., Sweet, M., Messina, R., & Schroeder, J. (1982). Principle of partial participation and individualized adaptations in educational programs for severly handicapped students. Journal of the Association for Persons with Severe Handicaps, 7, 17-27.

Birenbaum, A. & Re, M. (1979). Resettling mentally retarded adults in the community--almost four years later. American Journal of Mental Deficiency, 83, 323-329.

Brown, L., Branston, M., Baumgart, D., Vincent, L., Falvey, M., & Schroeder, G. (1979). Using the characteristics of current and subsequent least restrictive environments in the development of curricular content for severly handicapped students. AAESPH Review, 4, 407-424.

Brown, L., Branston, M., Hamre-Nietupski, S., Pumpian, I., Certo, N., & Gruenewald, L. (1979). A strategy for developing chronological age appropriate and functional curricular content for severely handicapped adolescents and young adults. Journal of Special Education, 13, 81-90.

Brown, L., Shiraga, B., Ford, A., Nisbet, J., Van Deventer, P., Sweet, M., York, J., & Loomis, R. (1983). In L. Brown, A. Ford, J. Nisbet et al. (Eds.), Educational programs for severely handicapped students: Vol, 13. Madison WI: Madison Metropolitan School District.

Bull, C. (1972). Prediction of future daily behaviors: An empirical measure of leisure. Journal of Leisure Research, 4, 119-128.

Bullock, C. (1986). Project Life (Leisure is for Everyone). Chapel Hill: University of North Carolina, Department of Recreation Administration.

Certo, N., Schleien, S., & Hunter, D. (1983). An ecological assessment inventory to facilitate community recreation participation by severely disabled individuals. Therapeutic Recreation Journal, 17, 29-38.

Chesseldine, S., & Jeffree, D. (1981). Mentally handicapped adolescents: Their use of leisure. Journal of Mental Deficiency Research, 25, 49-59.

Compton, D., Burrows, M., & Witt, P. (1979). Facilitating play and recreation opportunities for deaf blind children and youth. Dallas: North Texas State University, South Central Regional Center.

Datillo, J., & Barnett, L. (1985). Therapeutic recreation for individuals with severe handicaps. Journal of the Association for Persons with Severe Handicaps, 10, 194-199.

Donellan, A., Mirenda, P., Mesaros, R., & Fassbender, L. (1984). Analyzing the communicative functions of aberrant behaviors. Journal of the Association for Persons with Severe Handicaps, 9, 201-212.

Edgington, C., Compton, D., Ritchie, A., & Vederman, R. (1975). The status of services for special populations in park and recreation departments in the state of Iowa. Therapeutic Recreation Journal, 3, 109-116.

Gaylord-Ross, R., Haring, T., Breen, C., & Pitts-Conway, V. (1984). The training and generalization of social interaction skills with autistic youth. Journal of Applied Behavior Analysis, 17, 229-248.

Goetz, L., Schuler, A., & Sailor, W. (1982). Functional competence as a factor in communication instruction. Exceptional Education Quarterly, 2, 51-61.

Gollay, E., Freedman, R., Wyngaarden, J., & Kurtz, N. (1978). Coming back: The community experiences of deinstitutionalized mentally retarded people. Cambridge, MA: Ab+ Books.

Granger, C., & Wehman, P. (1979). Sensory stimulation. In P. R. Wehman (Ed.), Recreation programming for developmentally disabled persons. Baltimore: University Park Press.

Guess, D., Benson, H., & Siegel-Causey, E. (1985). Concepts and issues related to choice-making and autonomy among persons with severe handicaps. Journal of the Association for Persons with Severe Handicaps, 10, 79-86.

Hamilton, E., & Anderson, S. (1983). Effects of leisure activities on attitudes toward people with disabilities. Theraeutic Recreation Journal, 17, 50-57.

Hamre-Nietupski, S., Nietupski, J., Sandvig, R., Sandvig, M., & Ayres, B. (1984). Leisure skills instruction with deaf/blind severely handicapped young adults in a community residential setting. The Journal of the Association for Persons with Severe Handicaps, 9, 49-54.

Harter, S. (1978). Effectance motivation reconsidered. Human Development, 21, 34-64.

Hill, B., & Bruininks, R. (1981). Family, leisure, and social activities of mentally retarded people in residential facilities. Minneapolis: University of Minnesota, Developmental Disabilities Project on Residential Services and Community Adjustment.

Intaglia, J., Willer, B., & Wicks, N. (1981). Factors related to the quality of community adjustment in family care homes. In R. Bruininks, C. Meyers, B. Sigford, & K. Lakin (Eds.), Deinstitutionalization and community adjustment of mentally retarded people. Washington, D. C.: American Association on Mental Deficiency.

McGregor, G. (1982). Leisure and the domaines of home, school and the community. In P. Verhoven, S. Schleien, & M. Bender (Eds.), Leisure education and the handicapped individual: An ecological perspective. Washington, D. C.: Institute for Career and Leisure Development.

Murphy, J. F. (1981). Concepts of leisure. Englewood Cliffs, N. J.: Prentice Hall.

Nietupski, J., Hamre-Nietupski, S., & Ayres, B. (1984). Review of task analytic leisure skill training efforts: Practioner implications and future research needs. Journal of the Association for Persons with Severe Handicaps, 9, 88-97.

Park, H. S., & Goetz, L. (1985). Affect of young adults with severe disabilities in two differing educational programs. Manuscript submitted for publication.

Putnam, J., Werder, J., & Schleien, S. (1985). Leisure and recreation services for handicapped persons. In K. Lakin & R. Bruininks (Eds.), Strategies for achieving community integration of developmentally disabled citizens. Baltimore: Paul Brookes.

Ramey, S., & Watson, J. (1972). Nonsocial reinforcement of infant's vocalization. Child Development, 42, 291-297.

Ramey, S., & Watson, J. (1985). Recreation as a related service for students with handicapping conditions. Washington, D. C.: Office of Special Education Programs, National Consortium on Physical Education and Recreation for the Handicapped.

Sailor, W., Anderson, J., & Halvorsen, A. (1985). The California Research Institute on Integration of Students with Severe Disabilities: Annual Report. San Francisco: San Francisco State University.

Sailor, W., & Guess, D. (1983). Severely handicapped students: An instructional design. Boston: Houghton-Mifflin.

Salzberg, C., & Langford, C. (1981). Community integration of mentally retarded adults through leisure activity. Mental Retardation, 19, 127-131.

Schleien, S., & Larson, A. (1986). Adult leisure education for the independent use of a community recreation center. Journal of the Association for Persons with Severe Handicaps, 11, 39-44.

Schleien, S., & Ray, M. T. (1986). Integrating persons with disabilities into community leisure services. Minneapolis: University of Minnesota, Division of Recreation, Park, and Leisure Studies.

Schleien, S., Olson, K., Roger, N., & McLafferty, M. (1985). Integrating children with severe handicaps into recreation and physical education programs. Journal of Park and Recreation Administration, 3(1), 50-66.

Schleien, S., Porter, J., & Wehman, P. (1979). An assessment of the leisure skill needs of developmentally disabled individuals. Therapeutic Recreation Journal, 13, 16-21.

Schleien, S., Rynders, J., Mustonen, T., Fox, A., & Kelterborn, B. (1986). Use of a multi-element design to determine the effects of social levels of play on learners with autism. Manuscript submitted for publication.

Schleien, S., Wehman, P., & Kiernan, J. (1981). Teaching leisure skills to severely handicapped adults: An age-appropriate darts game. Journal of Applied Behavior Analysis, 14, 513-519.

Schleien, S., & Werder, J. (1985). Perceived responsibilities of special recreation services in Minnesota. Therapeutic Recreation Journal, 19, 51-62.

Shevin, M., & Klein, N. (1984). The importance of choice-making skills for students with severe disabilities. Journal of the Association for Persons with Severe Handicaps, 9, 159-166.

Taylor, S. (1982). From segregation to integration: Strategies for integrating severely handicapped students in normal school and community settings. Journal of the Association for Persons with Severe Handicaps, 7, 42-49.

Voeltz, L. (1982). Effects of structured interactions with severely handicapped peers on children's attitudes. American Journal of Mental Deficiency, 86, 380-390.

Voeltz, L., Wuerch, B., & Wilcox, B. (1982). Leisure and recreation: Preparation for independence, integration, and self-fulfullment. In B. Wilcox & T. Bellamy (Eds.), Design of high school programs for severely handicapped students. Baltimore: Paul Brookes.

Wehman, P. (1979). Recreation programming for developmentally disabled persons. Baltimore: University Park Press.

Wehman, P., Hill, M., Goodall, P., Cleveland, P., Brooke, V., & Pentecost, J. (1982). Job placement and follow up of moderately and severely handicapped individuals after three years. Journal of the Association for Persons with Severe Handicaps, 7, 5-16.

Wehman, P., & Schleien, S. (1981). Leisure programs for handicapped persons: Adaptations, techniques and curriculum. Baltimore: University Park Press.

Wuerch, B., & Voeltz, L. (1982). Longitudinal leisure skills for severely handicapped learners: The ho'onanea curriculum. Baltimore: Paul Brookes.

In Response to Lori Goetz

Importance of Communication Skills and Their Etiology in Planning of Recreation and Leisure Programs for Persons with Multiple/Profound Handicaps of Deafness and Blindness

Pamela Mathy-Laikko and Terrence R. Dolan

Introduction

I believe my role on this panel is to contribute the perspectives of an administrator of a university-based facility whose programs are concerned with the topic of deaf-blindness. I am the director of the Waisman Center on Mental Retardation and Human Development at the University of Wisconsin. The Waisman Center is comprised of a Mental Retardation Research Center (MRRC) and a University Affiliated Facility (UAF). As you probably know, there are eleven federally funded MRRCs in the United States--each conducting basic and clinical research on development of the nervous system and on abnormal developmental processes. Also, there are about 48 UAFs in the United States funded either by the training division of Maternal and Child Health or the Administration on Developmental Disabilities. These UAFs conduct interdisciplinary training and clinical/educational service programs on behalf of persons with developmental disabilities.

I might add, secondarily, that I am a psychologist interested in perception, particularly auditory perception, so my interests and earlier scientific endeavors are related to the topic we are discussing.

I was impressed with the comments made by Dr. Lori Goetz this afternoon. In a succinct presentation, she has identified some key issues for our consideration; she has placed her comments within the context of the currently available literature on the subject, and she has made some pointed and interesting recommendations for future

actions. What I would like to do in the next eight or nine minutes to to contribute comments or suggestions related to three areas mentioned in her presentation.

First, I suggest that our discussion of recreation and leisure programs for those who are deaf-blind should include a more concerted discussion of the individual differences that these individuals bring to a recreation and leisure program, especially the unique communication barriers associated with deaf-blindness.

Second, I have some specific comments concerning the issue of definitions, the integration of deaf-blind and noncompromised children and adults; and the issue of choice-making.

Third, I wish to emphasize one of Dr. Goetz's concluding points concerning the need for training (or, more accurately, for training and advocacy) associated with programs for persons with deaf-blind handicaps.

Comment #1

Dr. Goetz has addressed what she refers to as the best components or "best practices" in recreation and leisure programs, and has referred to many important components in those programs. I suggest that consideration of communication skills, the etiology of those communication skills, and the individual differences associated with those elements are equally critical variables.

In a presentation which dealt with special needs of persons with deaf-blindness and which was intended for use by rehabilitation counselors, teachers and other professionals working with persons with deaf-blindness, Koner and Rice (1984) divided deaf-blindness into four categories to be used "as a system in the search for a more individualized understanding of the deaf-blind person." The categories are based upon the time of onset of the combined disability, and include the following:

1. Congenitally deaf, adventitiously blind: the person who has been deaf since birth or early childhood and loses sight in adult life (e.g., a person with Usher's Syndrome);
2. Congenitally deaf-blind: the person who has been both deaf and blind from birth or early childhood (e.g., shows effects of maternal rubella);
3. Adventitiously deaf-blind: the person who loses both sight and hearing in adult life (e.g., through trauma, injury, etc.);
4. Congenitally blind, adventitiously deaf: the person who has been blind from birth or early childhood and loses hearing in adult life (e.g., a person with retrolental fibroplasia).

These categories are presented here as a brief illustration of the diversity of challenges that individuals who are deaf-blind may present to a recreation/leisure program. For example, a congenitally deaf-blind person with concomitant profound mental retardation, who has never participated in a recreation program, may need to be taught recreation skills. However, a person who has lost the use of one or the other or both senses adventitiously may need to learn new ways to participate in activities that he/she previously enjoyed and/or learn new activities.

In addition to considering the onset of the disability, recreational assessments and training programs might also consider in their planning the impact of other disabilities that are frequently associated with deaf-blindness (especially deaf-blindness of congenital onset). These include mental retardation and physical impairments. Also, it has been well documented that persons with deaf-blindness present unique receptive and expressive communication barriers and that these barriers also affect persons who attempt to communicate with them (for example, see discussions in Jensema, 1979 a, 1979 b, 1980, 1981; Curtis & Donlon, 1984; Konar & Rice, 1984).

This paper was presented by Terrence R. Dolan.

In summary, it is suggested that we consider carefully the etiological, cognitive, social and communicative characteristics of individuals as we plan future programs.

Comment #2

I would like to respond to three specific points made by Dr. Goetz. At the beginning of her presentation, Dr. Goetz discussed the definitions of leisure and of recreation, particularly from the perspective that the usual definitions do not provide much in the way of substantive and concrete information to be used by agencies and/or individuals seeking to improve recreation and leisure services for a specified group of people. Dr. Goetz attempts to pin down a definition of recreation/leisure by describing several components: (1) recreation and leisure takes place during discretionary time (nonwork time); (2) it can occur in variable locations; (3) it is defined as being a personally preferred activity; and (4) recreation/leisure activities can either be solitary activities or activities that one does in a social context (in the company of others). In defining recreation/leisure by time, place, and personal preference, the actual activities that may constitute recreation/leisure are left open. The "open-endedness" seems to serve a useful function in that it allows for a great deal of individual variablity in choice. However, such an open-ended definition may not suffice when considering its use by an educational or community agency responsible for recreation/leisure programs for persons with deaf-blindness. As discussed earlier, persons with deaf-blindness comprise a heterogeneous group for whom recreational activities encompass a broad range. One might consider, as a starting point, doing a study to collect information about what activities this population currently includes in its recreation/leisure repertoire. This information could be used to supplement existing data on recreational activities for various age groups. Such a list of activities could be used as a guideline which staff could use to develop, modify, and add new items to programs when necessary.

My concern here is that a definition that is too open-ended is subject to misuse. Although it may be useful in encouraging creativity, it may also encourage apathy on the part of agencies and organizations (particularly in a time of reduced resources). An agency, for example, could argue that it already has appropriate recreation/leisure programs because it satisfies the definition when, in fact, its program consists of large unstructured periods of time when the individuals just sit and do nothing.

In the middle of her presentation, Dr. Goetz discussed the importance of the integration of the person with deaf-blindness with nondisabled peers. Such integration, unless carefully planned, may not produce the anticipated benefits to deaf-blind individuals nor to their nondisabled partners. As mentioned earlier, persons with deaf-blindness have unique communication barriers. These barriers must be overcome in some manner, including perhaps the training of sign language and/or the used of alternative communication systems. In turn, the nondisabled peer must learn to receive and transmit information in an equally appropriate mode.

I know of no studies that have examined the social interactions among adults or children with deaf-blindness and their nondisabled peers. However, research has been done examining social interactions among five preschool children (ages 4-5) with severe-to-profound hearing impairments and five, same-age, nondisabled children (Arnold & Tremblay, 1979). All the children were enrolled in an integrated preschool program. A sample of playground behavior of each child was recorded on videotape and analyzed. Tapes were coded for the frequency of occurrence and initiator/receivor roles for nine behaviors (vocalizations, gestures, approaches, physical contact, imitation/social play, give object, take object and aggression). The results indicated that hearing children were more likely to approach, engage in social play, vocalize to, and physically contact other hearing children. In contrast, the children with hearing impairments showned no definite peer preference. The authors concluded that nondisabled children may have found attempts to interact with hearing-impaired peers less socially reinforcing because of their lack of comparable communication skills.

The results of the above study suggest that successful integration programs must consider the communication skills of the participants. It may be that more successful groupings would be comprised of individuals of different chronological ages but who are matched in communicative ability. Preliminary results of research now being conducted at the Waisman Center suggest that this is so.

Dr. Goetz also suggested the importance of the component of choice in the conduct of recreation/leisure activities. That is, it is important for the participant to be involved in choosing the activity. I concur. The process of selection, however, may be complex and the results may be misinterpreted. Children with a conventional language system (e.g., sign language) may understand all of the options available to them and communicate their choice effectively. Persons without such communicative skills may not understand the range of opportunities available and/or have difficulty communicating their final choice. It may be that the development of new techniques to assess the wishes and attractions of these persons without a conventional communication technique, based upon observation of that person in various situations, may assist in deducing the choice the individual makes. Research is needed to develop such effective assessment techniques.

Comment #3

Concerning my last comment, Dr. Goetz made a point about the need for training programs to improve and increase the recreation/leisure opportunities for persons with deaf-blindness. I strongly endorse her recommendations and suggest that such programs are needed for both professionals and paraprofessionals. I believe that these training programs should stress the development and use of communication techniques used by persons with deaf-blindness, observational assessment techniques, and the range of variability of behavioral characteristics associated with deaf-blind persons with differing etiologies, cognitive status, communication ability, and communication mode.

Finally, how do these considerations affect the role, or potential role of university-based programs (MRRCs, UAFs, R & T Center, etc.)? I believe these programs have a responsibility to become more involved in the development of such training programs as well as in their advocacy. The Waisman Center is not unlike many other UAFs. At the Waisman Center, there are scientists and clinicians from psychology, engineering, physiology, speech/language, audiology, counseling, rehabilitative medicine, and many other disciplines, who are involved in research and programming for persons with developmental disabilities and a concommitant communications impairment. These experts have the capability and experiences to conduct interdisciplinary research on problems associated with deaf-blindness, and some are experienced in the conduct of clinical and educational programs designed to work with persons with deaf-blindness. They also conduct training programs for professionals and paraprofessionals within their respective regions, and they conduct technical assistance and consultation programs in which they collaborate with the various agencies and organizations that work with persons with developmental disabilities. I believe it is important for UAFs and other univeristy programs to make a more concerted effort in training and consultative efforts pertaining to recreation and leisure programs for persons who are deaf-blind, and to work with those agencies who are responsible for such programs.

How we may contribute, and the specifics of what needs to be done by all agencies and organizations, I assume, will come out of discussions such as those you are having there now. I believe that discussions at conferences such as this one, and papers such as the one contributed by Dr. Goetz a few moments ago, can provide the basis for effective planning and, subsequently, to more effective recreation/leisure programs.

References

Arnold, D. & Trumblay, A. (1979). Interactions of deaf and hearing preschool children. Journal of Communication Disorders, 12, 245-251.

Curtis, W. S., & Donlon, E. T. (1984). A ten-year follow-up study of deaf-blind children. Exceptional Children, 50, 449-455.

Jensema, C. K. (1979). A review of communication systems used by deaf-blind people, part I. American Annals of the Deaf, 124, 720-725.

Jensema, C. K. (1979). A review of communication systems used by deaf-blind people, part II. American Annals of the Deaf, 124, 808-809.

Jensema, C. K. (1980). A review of communication systems used by deaf-blind people, part III. American Annals of the Deaf, 125, 9-10.

Jensema, C. K. (1981). Reports of communication method usage by teachers of deaf-blind children, American Annals of the Deaf, 126, 8-10.

Konar, U., & Rice, B. D. (Ed.). (1984). Strategies for Serving Deaf-Blind Clients (Eleventh Institute on Rehabilitation Issues). San Antonio, Texas: Arkansas Research & Training Center in Vocational Rehabilitation, University of Arkansas, Arkansas Rehabilitation Services.

In Response to Lori Goetz

A Parent's Viewpoint

Barbara Ryan

About four years ago I went through what's called a Parent Interview or "Significant Other" Interview. The reason for the interview is to establish the critical needs for the child and how to teach them. It takes into consideration what the parents feel is critical for that child.

As I went through that interview it went very nicely. They started out by asking me what my child was doing on a day-to-day basis, what my child did in the morning before she went to school, what she did when she got home. That hour went very nicely.

They asked what did she really like the most. I liked telling about that.

Then they went into, What does your child do that's special? What does your child do during the week that's special? What does your child do on the week-end that's special? I kind of went into a state of shock when that was asked, and some real guilt feelings hit me hard. Because I was at a new stage, I was in transition with my daughter going from childhood into adulthood.

It was easy for me when she was a child to have her doing recreational-leisure kinds of activities with the family because I had two other daughters. So it was a natural flow. It was a natural involvement and it felt really comfortable. Then my other two daughters grew older—they didn't need the family structure that was provided before, so there was a drop-off. And I was aware of it and didn't know quite how to handle it.

So it hit me when that was asked of me, face to face. They didn't mean to challenge me like that. They didn't realize that I went into emotional trauma on the inside, feeling very, very guilty because I really hadn't been providing my daughter with an ongoing recreational-leisure type program that was very planned.

There was no more swimming activity on a weekly basis. There was no more horseback riding because we had gotten rid of the horses. There was no more--we had gone hiking a lot. All those kinds of things that worked very well within our family unit were gone because the family changed. And I really had been feeling guilty about that. I felt guilty about it for a long time.

Today, I feel differently. I don't feel guilty any longer, even though I still don't plan anything systematically. I now don't feel that it's totally my responsibility. I can see where there are agencies and other people that are going to help me do this. And I have reached out and tried to provide my daughter with another person, other than myself, to entertain her and provide her with recreational-leisure time.

The thing I've done is this: I hired a companion for Doria. Besides having a live-in housekeeper to make sure that there is somebody in the household that provides her with her meals and makes sure she gets on the bus in the morning--that's kind of a very critical issue—I do have an age-appropriate companion for her. I found this person through the university that was close by. And it has worked out beautifully. And even though there are communication problems, somehow it works out beautifully when you have some commonalities. And the fact is, that my daughter is interested in boys, and she gets a big kick out of the fact when the companion brings her boyfriend over and she can giggle and flirt.

She does like going to movies. And this person is not as hung-up as I am about the noises she makes in movies. She thinks it's funny. I get kind of embarassed.

She gets excited and is happy to take my daughter down to the beach with her and do those kind of free-flowing recreational things. It has worked well. I was fortunate to find somebody that does a very, very good job, and that I can trust. And I know it's an ongoing challenge through the years. I'll have to keep finding companions for her . . . .

The challenge is even going to be greater as our children get older: how to provide age-appropriate recreational-leisure kinds of skills. The agencies that are responsible should be more responsible. They aren't aware of this responsibility yet, and I think it's going to be up to parents to make sure they do become aware of this responsibility.

There are some things they do provide, but we as care providers didn't know to ask for them. Transportation is a prime example of something that is available, at least through our developmental disabilities area, the regionals in California. Transportation is available for our people, but you have to ask for it. You have to practically demand it—it doesn't come easily.

Tying in parks and recreation, and going back to the communication factor, how are we going to improve those areas? I think probably having a primary person involved in these activities is essential, like having a companion. How do we train those companions? I don't know. That is something I think we're going to have to look at and we're going to have to deal with in a very, very specific way. I think it can be done. Actually I'm pretty excited about it.

As far as the ongoing education of our children goes, I've been very interested in the past few years about the Adaptive Physical Education coaches that have been involved in the educational system. I've been disappointed in them. I cannot begin to tell you how horrified I was to walk in and see what the Adaptive Physical Education teacher was doing with my daughter, and that was before I even knew about age-appropriate activities. The teacher had her crawling through little tunnels made for preschool children, and she was 14 or 15 years old. I mean that's not really very appropriate.

Start insisting that those agencies and those people that are trained in the Adaptive Physical Education teacher programs be more appropriate with our children as they are growing through the years.

There are other agencies that could be responsible for these recreation-leisure kind of activities. How about looking to the arts, all the different types of art, the dance, the music. And I know I'll be challenged by the fact that the children can't hear.

You're right, they can't hear. But my daughter is 21 now, and I do take her dancing, into a bar that has the flashing lights, that has the loud music, and she can stand right next to the speaker.

Now you have to keep an open mind about this because my daughter isn't going to dance. She does not like to dance. However, she is stimulated by the vibration and the flashing lights, and she does like to stand there on the dance floor. I'd like to find some nice looking young man to maybe dance around her and maybe hold her. She does like to slow dance, occasionally. And then she wouldn't look so bizarre, out in the public on a dance floor where there are social kinds of situations.

These kinds of issues, I think we need to really look at in depth. We need to look at the age-appropriate kinds of activities that are involved. We need to really work very, very hard at being daring and very, very willing to risk in our thinking about what is leisure and what is recreational.

Report of the Working Group on Recreation and Leisure

Group Members

Martin Adler	Norman McCallum
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John Datillo	Barbara Ryan
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Report prepared by Rosanne Silberman

Philosophy/Belief Statement

The goal of implementing recreation/leisure programs is to improve the quality of life for a person with deaf-blindness and other profound handicaps. We have defined some leisure needs, have suggested a number of characteristics of the desired recreation and leisure programs to meet these needs, and have addressed some avenues of implementation and logistical considerations. Each of these persons, from the lowest functioning level upward, must have access to frequent and consistent recreational/leisure programs. These programs are a priority in the realistic pursuit of developing an appropriate leisure lifestyle that overcomes unique communication barriers and, most importantly, enhances the individual's quality of life.

Recreation and leisure play a vital lifelong role in the lives of all human beings, including those who are deaf-blind, because recreation and leisure participation signficantly enhance the quality of life.

While the terms recreation and leisure are frequently used interchangeably, their meanings are actually quite different. Recreation refers to structured activities, either

on an individual basis or in a group. One can get involved in recreational activities which may or may not include a leisure state. Leisure refers to a state of mind which gives the person choice and control and thereby allows him to experience enjoyment, pleasure, and satisfaction. The distinction between these two terms is an important consideration in planning recreation/leisure programs for these individuals.

Program Approach and Characteristics

Approach. Due to concomitant sensory and physiological deficits, isolation and poor self-image are inherent in the life of the person with deaf-blindness and other profound handicaps. These conditions must be counteracted by meeting the following needs within the areas of recreation and leisure. These include the need for the individual to

1. have exposure to opportunities for recreation and leisure on a daily basis;
2. Develop skills enabling participation at an optimal performance level;
3. develop isolate skills (e. g., press a switch to cause vibration or a cassette recorder to turn on);
4. develop interaction and group recreation skills;
5. be involved in chronological, age-appropriate recreation activities and materials;
6. be provided with opportunities to communicate choices and preferences;
7. be involved in interactions with others.

Characteristics. Recreational/Leisure Programs should

1. coordinate leisure with other aspects of a person's life (e. g., work and residential environments);
2. include individual and group participation options;
3. occur in variable locations, including natural environments such as the home or in a park;
4. provide opportunities for integration with nonhandicapped peers through reciprocal activities among participants;
5. provide appropriate transportation to and from a barrier-free location whenever necessary for the recreation activity;
6. be future oriented and be sensitive to preferences of the family and significant others;
7. focus on the development of lifelong skills;
8. provide for a range of skills to facilitate development of a repertoire of leisure opportunities;
9. encourage the development of communication skills in order to respect and facilitate choices made by the individual;
10. provide skill-building opportunities to enable individuals to participate in decision making relevant to leisure;
11. conduct assessment of individual capabilities and an analysis of the activity to determine level of participation (partial or full).

Examples of Recreation and Leisure Programs. These are programs in which individuals with deaf-blindness and other multiple profound handicaps can participate on varying levels:

Softball.

1. Full participation: the individual does the activity independently with necessary adaptations (noise in ball, ball on tee).
2. Partial participation:
   a. the individual runs from base to base with a peer partner;
   b. the individual in wheelchair is pushed by partner from base to base;
   c. given hand-over-hand assistance, the individual pitches the ball.

Bicycle.

1. Full participation: the individual rides independently with necessary adaptation (adult tricycle).
2. Partial participation: the individual rides on a tandem bicycle with another person.

Watersports (Floating).

1. Full participation: the individual floats in the pool with the only adaptation in doing so in the shallow end of the pool.
2. Partial participation: the individual wears a life preserver or arm floats or uses an inner tube.

Additional examples where individuals can participate fully or partially.

1. Community opportunities to derive multisensory experiences, such as amusement park rides, spectator sports, camping, fishing, hayrides, horseback riding, aerobics, roller skating, museums, and zoos with tactile (petting) sections.
2. Home/school opportunities, such as aerobics and swinging (for vestibular experiences), lotion application, fingerpainting, weaving, ceramics, and macrame.

Issues

Personnel

In order to bring about the programs described above, a variety of types of personnel with different training and experience will be required. These include professionals (e. g., therapeutic recreation specialists, recreation coaches, teachers, case managers) who will be needed for evaluating/assessing, planning, coordinating, implementing, and monitoring the newly mandated recreation and leisure programs. In addition, paraprofessionals and others including parents, volunteers, and peers will be needed to assist in these programs and in the hands-on participatory activities that may be required. These personnel may be employed in state, county, or community agencies as well as in schools, parks, and recreation departments, or in community and neighborhood projects.

In some cases, personnel may be currently available as existing staff who will be responsible for broadening their current responsibilities. To do so, they may be required to participate in further inservice training, depending on their expertise, in the following areas: recreation, leisure, alternative communication techniques, and the effects of the combined sensory impairments on individuals with deaf-blindness. In other instances and whenever possible, personnel who possess specialized training in the area of therapeutic recreation should be recruited. Many individuals in this field have only served in segregated settings, and now it is critical to utilize their expertise in the community.

Logistics Regarding Recreation and Leisure Programs

Appropriate management decisions should be considered in all logistical aspects. These aspects include availability.

1. Are the activities accessible? (These are concerns regarding transportation and architectural barriers.)
2. Are the activities available in home or local community?

Cost Factors

1. Which and how many staff members are needed?

2. What are the required fees, and are they valid, considering the preferences of the individual (e. g., horseback riding which is expensive and yet can be pleasurable to this population)?

Safety and Risk Factors

1. How is the consideration of the unique needs (such as health status) of the individual balanced with opportunities for pleasure which have some degree of risk involved (e. g., swimming and tubing)?
2. How can the service providers and parents balance the risk factors to maximally enhance the quality of life of the individual?

Recommendations

Implementation of Recreation and Leisure Programs

The group wholeheartedly recommended that wherever legislative responsibility exists for funding various types of programs, it should be mandated that recreation and leisure services, with characteristics such as those described above, be incorporated into the funded programs in order to ensure that each person with deaf-blindness and profound multiple handicaps has an appropriate recreation/leisure program within his own home community. For example, recreation/leisure programming should be included in the following:

1. Individual Education Plan (IEP),
2. Individual Transition Plan (ITP),
3. Individual Rehabilitation Plan (IRP),
4. Individual Habilitation Plan (IHP).

Communication

Appropriate communication is a necessary skill for all personnel, including volunteers, parents and significant others involved in the daily life of the person with deaf-blindness and profound multiple handicaps. The group strongly encourages the development and utilization of communication skills and alternative communication systems, modes, and strategies in the development and implementation of recreation and leisure programs.

Program Costs

Persons in this population need various support services. The individual with deaf-blindness and profound multiple handicaps has to maintain various levels of dependence upon various resources, including personnel, in order to survive and to grow. This necessary dependence requires an increased cost factor which is absolutely necessary in order to meet dependency needs.

Integration

Recreation and leisure programs should utilize existing community agencies and facilities which serve all persons. Appropriate personnel should help with any necessary preparation, awareness, and understanding of those with deaf-blindness and profound multiple handicaps prior to actual integration, if possible.

Continuity of Service

As these individuals come of age and leave the educational system, the following recommendations are made to ensure continuity of services:

1. The federal government should require states to designate a lead agency to be responsible for overall case management. This agency needs to maintain a quality assurance evaluation system for persons with deaf-blindness and other profound handicaps across life domains including residential, vocational, health, and recreation/leisure.
2. Parent representation should be included in all levels of decision making by the lead agency (from "board level" down).
3. The parent/guardian should be included in all planning and decision making concerning that individual's program from the very beginning.
4. The designated lead agency should have a recreation/leisure specialist to address individual recreation/leisure needs or coordinate with a specialist from a community recreation program to ensure appropriate recreation/leisure services.